



WOUNDED WARRIOR PROJECT

STATEMENT FOR THE RECORD

**SUBCOMMITTEE ON HEALTH
COMMITTEE ON VETERANS AFFAIRS
U.S. HOUSE OF REPRESENTATIVES**

**VETERANS AFFAIRS' CAREGIVER PROGRAM: ASSESSING CURRENT
PROSPECTS AND FUTURE POSSIBILITIES**

DECEMBER 3, 2014

Chairman Benishek, Ranking Member Brownley, and Members of the Subcommittee,

Thank you for inviting Wounded Warrior Project (WWP) to provide our perspective regarding the Department of Veterans Affairs' (VA) Family Caregiver Program. Having led the charge for Public Law 111-163, the Caregivers and Veterans Omnibus Health Services Act of 2010, we remain committed to serving this generation of injured veterans and their caregivers through advocacy and programmatic supports and are dedicated to ensuring the vital support and compensation provided under the program is strengthened and that flaws in the VA's implementation of that law are resolved.

Maintaining very close ties with disabled veterans and their families, WWP has seen how profoundly a warrior's injury changes an entire family's life. One of the many family members with whom WWP has worked described it well in a previous hearing in front of this Committee:

Confronted by severe, life-threatening injuries sustained by a spouse, fiancé, child or other loved one, families must make sudden life-altering changes. Family members may be forced to take extended leaves of absence or permanently leave their jobs to be at the service-member's bedside, beginning a journey of what may become years-long or even a lifetime of committed care. These are acts of love and self-sacrifice. But as the sister of a profoundly disabled veteran, and as a friend of many, many caregivers across the country, I can tell you that, while the decision to care for a loved one may come easily, caregiving can take an extraordinary toll – emotionally, physically, and economically.¹

Working daily with family members of warriors who have sustained severe or catastrophic injuries and need ongoing care or assistance, WWP saw the profound toll and the lack of

¹ *Meeting the Needs of Family Caregivers of Veterans*: Hearing before the Subcomm. on Health of the H. Comm. on Veterans Affairs, 111th Cong. (June 4, 2009) (Testimony of Anna Frese).

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assistance for the caregiver. While caring for severely disabled warriors – sometimes for years and without assistance – many caregivers have left their jobs, exhausted savings, and suffered tremendous strain to their own health in order to provide the very best care for their loved ones. The need to provide caregivers access to mental health services, respite options, health coverage, and some modest financial support has been real and pressing. Government programs and services have almost exclusively focused on recovery, rehabilitation, readjustment, and compensation for the warrior. However, caregivers’ needs were not addressed until passage of the caregiver-assistance law.

Over four years ago, this Committee helped craft historic legislation that established the framework for a VA program that now provides critical supports to family caregivers of seriously disabled veterans. This legislation recognized the risk that the extraordinary toll of caregiving could overwhelm the caregiver – whether physically, emotionally, or financially – and result in unwanted, but very costly institutionalization. This legislation proposed, therefore, that VA provide support services to help shore up those vulnerabilities. Specifically, we advocated for a program that would provide caregivers with needed training, technical support, mental health counseling, health care coverage, respite care, and a modest financial stipend.

This Committee has played a critically important role – not only in shaping the caregiver law – but in jump-starting and accelerating a process that over the last several years has provided long-awaited help to over 16,000 families. This Committee’s oversight of the program to ensure VA complies fully with the law is equally important.

A year after the law was enacted VA finally implemented the program with the adoption of interim final regulations. Although we and other advocates raised concerns about those implementing regulations in formal comments, VA has yet to answer – let alone remedy – problems with the program by promulgating final regulations. Several of these unresolved issues are sources of real frustration for caregivers. Vagueness and ambiguity in those regulations have resulted in wide variability in determinations of eligibility and support, with evidence of clearly erroneous decisions creating hardship.

Additionally, the interim final regulations leave “appeal rights” unaddressed (including appeals from adverse determinations of law). They set unduly strict criteria for determining a need for caregiving for veterans with severe behavioral health conditions, including veterans with Traumatic Brain Injury (TBI). In addition, the vagueness of the regulations, in terms of clinical decision-making, also invites arbitrary, inconsistent implementation. These are serious issues. We ask your help in resolving these long-outstanding concerns, as well as in easing detailed the Veterans Benefits Administration (VBA) reporting and oversight requirements on Veterans Health Administration-recognized (VHA) caregivers who are also fiduciaries for their loved ones.

To illustrate the point, one caregiver of a veteran who is rated 100% disabled for Post-Traumatic Stress Disorder (PTSD) and who needs his wife’s assistance because he cannot manage safely on his own, cannot drive, and cannot manage his own funds (VBA has designated his wife his guardian and the fiduciary for his funds). Yet a VA psychiatrist, apparently with no input from

any other VA staff, unilaterally determined that the veteran's wife is not eligible for caregiver-assistance because the clinician's goal for the veteran is to become more independent. That would certainly also be his wife's goal, but the issue is that the warrior needs caregiver-assistance now, and the possibility that he might one day achieve greater independence cannot be a basis to deny a family caregiver the support she and the veteran need now.

VA's regulations also include deeply flawed criteria for assessing the extent of needed caregiver-assistance. In a WWP-conducted survey of caregivers, more than one in four (28%) respondents expressed disagreement with the VA's assessment of the number of hours of caregiver-assistance their veteran required.²

As the lead advocate for the caregiver-assistance law, WWP will continue to press for regulatory change, or pursue other avenues as needed. WWP will also work to ensure that the support provided to caregivers under this new law is not compromised (in the case of caregivers who serve as fiduciaries for a disabled veteran) by unreasonable demands under the VA's fiduciary program. There is an appropriate place for fiduciary oversight. From the perspective of family members who for years have sacrificed to care for a loved one and also take on responsibilities as a fiduciary, oversight under that program can be not only confusing, but demeaning. WWP will work to ensure that the VA's fiduciary program better accommodates the needs of these warriors and their families.

Overall, it is clear VA faced challenges in implementing this new program, and that many dedicated staff worked hard to launch it. The process has gone relatively smoothly for numbers of families, while some have encountered problems. We have worked with many others who are still in limbo, waiting for applications to be processed and unsure of what comes next.

But we are most concerned about VA's implementing regulation (which governs the determination and delivery of benefits to caregivers) because it still fails to get some issues right. As a result, some families will likely be shut out; others will likely not get the level of help the law requires. What is quite clear is that the rules discouraged many from even applying.

Let us acknowledge that VA's implementing rule is a marked improvement over its initial implementation plan. Unfortunately that regulation needs a lot more work. Let us illustrate by discussing several of our concerns with VA's eligibility criteria, inconsistency in how eligibility is determined, appeals process, and how the stipend is calculated.

Eligibility Criteria & Mental Health

As is well recognized, TBI and PTSD are the signature wounds of this war. Many of the problems we hear regarding VA's implementation are from the families of warriors with those invisible wounds. Typically, because of the severity of one or both of those conditions – these family members feel they can't leave their warrior alone. As one caregiver put it succinctly,

² Wounded Warrior Project Survey of Caregivers of Wounded Warrior Alumni (2012). With more than 330 caregivers participating, the survey respondents reported that the principal condition or conditions requiring caregiver-assistance for their veteran were a mental health condition (66%) and/or traumatic brain injury (62%).

“[My warrior] does not need care around the clock, but I have to be available 24/7.” Each case differs. Often, the warrior lacks full cognition or judgment to be fully aware of danger. In other instances, a warrior’s behavior may be erratic, marked by lack of impulse-control, or even reflect a level of anxiety such that the individual sleeps with a weapon under his pillow or otherwise leaves family fearful of possible suicide-risk. In these kinds of instances, a family member typically stays with the veteran for much of the time to ensure the warrior’s safety. Where those behaviors are due to traumatic brain injury, VA’s eligibility rule appears to cover such circumstances. In instances where that same safety risk or other similar problem is due to PTSD, depression, or anxiety, however, it seems much less likely that VA will provide caregiver assistance under its new rules.

In contrast, the law very clearly addresses circumstances involving the veteran’s safety or related vulnerability. It states that a need for caregiver assistance can be based on a veteran’s “need for supervision or protection.” That criterion would address the full range of situations we have described. But in the case of a veteran who has PTSD, depression, or anxiety, VA has unnecessarily established a separate, much more restrictive rule. In the case of a veteran with PTSD or other war-related mental health condition, VA’s rule says the veteran must be bedridden, delusional, or virtually suicidal to be eligible for caregiver-assistance. And unlike a veteran with a physical impairment, who may be eligible if only a few hours of help daily are needed, a veteran with a mental health condition must require “constant supervision.” This kind of disparity is not only unfair, it is inconsistent with the provisions of the caregiver law which draw no distinction between TBI and PTSD.

Additionally, the law’s exclusion of support for service-connected illnesses has resulted in depriving veterans with significant caregiving needs of caregiver-support and services. Many of these illnesses, like amyotrophic lateral sclerosis (ALS) and multiple sclerosis (MS), are profoundly disabling and denying caregiver support and compensation for these conditions compels congressional action.

Clinical Determinations

A second area of concern is how VA’s eligibility criteria are being applied at medical centers around the country. WWP conducted a survey to understand the experience of families who have applied for assistance under the caregiver program. Among the findings, the survey responses suggest that there is variability from facility to facility as to who determines a veteran’s need for caregiver assistance, as well as frequent failure to communicate to caregivers how these eligibility determinations are made. Asked their understanding of who determines a veteran’s need for caregiver-assistance, more than one in five caregivers expressed the understanding that it was the primary care physician; one in four responded that it was the clinical team; while more than four in ten were unsure. Almost one in five respondents indicated that VA has not explained the process or criteria they will use to determine the veteran’s need for caregiving assistance. Feedback from caregivers going through the application process suggests that the breakdown in communication occurs between VA and veterans and their caregivers, and also between VA Central Office and the field.

Let us share one example. For the past several years, a caregiver has provided almost constant care and supervision for her husband who suffers from PTSD, TBI, and persistent short-term memory stemming from injuries. The caregiver submitted an application for caregiver assistance and was contacted shortly afterwards by a nurse practitioner and advised that the application had been denied. The nurse, without either reviewing the veteran's medical records or consulting the veteran's longstanding care team, "determined" on the basis of the veteran's compensation and pension examination records that he didn't need assistance in performing activities of daily living – and thus concluded, accordingly, that he was not eligible. Among the many errors involved was to overlook the fact eligibility could be based solely on a need for supervision or protection, and that these decisions are to be made by an interdisciplinary team.

The veteran's occupational therapist was surprised by the decision and lack of dialogue, and drove to the VA Medical Center for an in-person meeting with the nurse practitioner, after which the eligibility decision was ultimately reversed. While this story ended favorably, it offers a stark illustration of problems other families have encountered with vague VA rules on clinical eligibility determinations. In this instance, but for a very dedicated and well-informed occupational therapist and psychiatrist, this certainly could have ended differently, with much greater distress and headache for the caregiver and veteran.

Another survey respondent's experience highlights the risk of error in what may be a too-brief clinical assessment:

My husband was interviewed by his VA physician, but I was not allowed to go in and assist him and help him remember things and help give an accurate picture of his functioning and health. His physician had only seen him a couple of times, we were told this was the reason he was going in for an interview/assessment. The assessment was supposed to provide the understanding of my warrior's needs. Since I was not there, and my warrior does not recall the entire interview, I do not know if the doctor really got a good understanding of the situation.

Appeals

While the above-cited cases may be outliers, they do raise the question, how can a veteran or caregiver appeal an adverse medical or legal decision? The current review opportunity, for stipend purposes, following a denial of benefits or Tier level is only subject to review by the VHA Medical Center Director. VHA physician staff conducts a clinical assessment review, yet prohibits a private physician's involvement or review of other medical opinions regarding the veterans' need for care. In contrast to decisions administered by VBA, VHA caregiver decisions are denied the opportunity for a personal hearing to bring forth additional evidence or provide sworn testimony under the guidance of an accredited representative. No other such decisions under VBA are afforded this exclusion. All decisions by the VBA are given specific due process and appellate rights. We believe VHA decisions regarding caregiver benefits should not be exempt from this review.

The implementing regulation is completely silent on this important issue. Yet it is essential that VA establish systematic recourse for those caregivers and disabled veterans who may be unduly denied benefits. Feedback WWP has received from caregivers indicates that they are unaware of where to turn in the event that they disagree with a VA determination. This is an issue VA must address as more veterans and their caregivers apply for this benefit, particularly given the potential for error.

Respite

Our survey also showed that while almost three quarters of caregivers were aware of VA opportunities for respite care, a remarkable 93% had not used VA-furnished respite. While respite may be available, it is clear that current options do not meet the critical need for this kind of care. Families with whom we work have shared concerns about safety and respite environments that don't provide a stimulating or engaging atmosphere for the warrior or is not suited to their disability. Opportunities for caregiver-respite should be expanded to provide care that these families will actually use.

Loss of Caregiver Benefits

The interim regulations provide direction for determining the amount of a stipend award and for revoking caregiver benefits. In the case of a revocation, caregiver support may continue for 30 days. Despite the regulation's silence on the matter, we have heard VA medical centers sometimes reduce caregiver stipend amounts, even though the regulation provides no such direction. A sudden, sharp reduction or termination of stipend support can cause a caregiver severe financial hardship. Additionally, the interim regulations provide that in the case of caregiver-status being terminated, VA is to assist the individual to transition to alternative health coverage. The regulation makes no allowance, however, for circumstances where the burden of caregiving itself is a substantial factor in the individual's inability to sustain the role of caregiver. These issues need to be considered to prevent undue hardship and to more effectively plan for the long-term needs of warriors and their families.

Stipend Calculations

Another particularly problematic area relates to determining the amount of a stipend VA will provide a family member designated as the primary caregiver. Since many caregivers can no longer work outside the home and often care for their loved ones on a full-time basis, the stipend was to provide some modest level of financial assistance (tied to the area wage rate of a home health aide).

The law directs VA to develop a methodology for calculating the amount of a stipend, which is to be based on the amount and degree of personal care services the family member provides. But the scoring methodology VA has developed is deeply flawed, particularly for those whose need for caregiving is based on a need for supervision and protection. In other words, the methodology does not provide a reliable tool for gauging the caregiving needs of a veteran with traumatic brain injury, PTSD, or depression.

Specifically, under VA's criteria, a veteran's need for caregiver assistance is rated on a scale of 0-4 for each of seven criteria associated with need for assistance with activities of daily living and the need for supervision. With respect to each criterion (such as need for assistance in performing a particular activity of daily living; having difficulty with planning and organizing; or posing a safety risk), VA clinicians are to assess the degree to which the veteran needs assistance in that particular domain, from having no need for assistance (scored as "0") to needing total assistance (scored as "4"). The number of hours of caregiving-assistance a warrior needs is determined based on how high they score on these measures.

A couple illustrations may be helpful. Take the case of a veteran who sustained a severe TBI in an IED blast, but after a lengthy rehabilitation is able to independently perform all activities of daily living and has no serious cognitive deficits. In this case, the lasting impact of his TBI manifests itself in severe mood swings and sometimes aggressive and violent outbursts. Because he is unable to control these behaviors, even with the assistance of medication, he is unable to work and his wife accompanies him everywhere. She helps him avoid the problems his behavior may cause, get to his medical appointments and maintain some level of social interaction.

In another case, a veteran has lost several friends after multiple tours to Iraq, and suffers now from severe chronic depression. While he has no physical limitations, he is utterly without energy, has difficulty even getting out of bed, cannot concentrate on tasks, and experiences feelings of hopelessness. Medications have not alleviated his symptoms, he is largely homebound, and his mother maintains virtually full-time watch to be sure he that he doesn't harm himself.

Applying VA's current rating scale, in both cases the veteran might score a "4" based on total inability to self-regulate, perhaps another "4" based on safety risk, and another "4" based on inability to plan or organize. In each case, though, with no other pertinent areas of needed assistance, the total score would be "12." The VA rule, however, states that a veteran with an aggregate score between 1 and 12 is presumed to need only 10 hours/week of caregiver assistance. The rule makes no allowance for rebutting that presumption.

These examples are real; let us share the frustration expressed by one of the respondents in our caregivers' survey as she explained that the scoring system fails to take into account the gravity of her husband's needs:

I was told that my husband scored in the low Tier level I, with an 11. This only allows 10 hours [of caregiving] a week, approximately \$426 a month. I don't agree with this because my husband needs continuous supervision due to his TBI, PTSD, mental health and also sometimes 2-3 days a week requires bed rest due to physical pain. So 10 hours a week is like about 1.42 hours a day. I have to help him remember to take medications 3 times daily, assist with cooking, driving, medical appointments, just overall supervision for his safety. 10 hours a week is nowhere near the time I spend caring for him.

These scenarios clearly reflect how important it is that VA revise the current stipend-calculation methodology. What is clear is that requiring a high aggregate score across multiple criteria makes no sense when a single deficit or impairment may dictate a need for total care. Does it make any sense, for example, that a veteran who cannot be left alone at all for safety reasons – and has no other limitations – should be deemed to need only about an hour and a half of caregiving help daily?

It is not unusual that a veteran who has sustained a severe TBI, for example, may regain lost function in many domains, have no physical limitations, and may still need to have a loved one close by on a more or less full-time basis because of a single issue – whether it is erratic behavior, severely impaired judgment, or safety. In the case of a veteran whose condition creates a need for supervision or protection it makes little sense for VA to assume that a need for full-time caregiving can only exist when the veteran has multiple needs. This system reflects a fundamental underestimation of both TBI and mental health conditions like PTSD.

The problems with the stipend actually go deeper. Even in circumstances where a veteran is deemed to need total assistance, VA sets a cap on the stipend amount—limiting any caregiver’s stipend based on the presumption that 40 hours a week of care would be provided. VA’s rule does not address the fact that our disabled veterans’ needs rarely conform to a 9-to-5 business day, and makes no provision for those additional hours of likely needed caregiving.

We understand that the intent of this cap is that caregivers shouldn’t have to work unreasonably long hours, and that additional care would be provided by others, such as home health aides. Yet the rule is silent on this. Can caregivers count on it? Even if VA were generally to provide such assistance, veterans and caregivers who reside in rural areas are not likely to have access to such sources of care. Given these realities, we have urged VA to revisit the issue and lift the cap where needed so that the stipend amount more reasonably reflects the hours of caregiving actually provided.

Caregiver Program’s strengths and weaknesses

While WWP believes that VA must make changes to its final regulation (and submitted extensive recommendations in response to VA’s Federal Register notice regarding its VA’s interim final rule), we also recognize the progress VA has made in launching this multi-faceted program.

Many caregivers who responded to our survey commented favorably on the ease of filing the initial application and the timeliness with which VA had made contact with caregivers and veterans after the initial submission. Among those surveyed who had reached the stage of a VA home assessment, many respondents commented that VA employees had been professional, thorough, and appeared to be genuinely invested in the health of both the veteran and the caregiver. One respondent characterized the home visit as the most positive interaction she has had with VA employees to date.

Yet despite these positive experiences, caregivers tended to have greater frustration with what appears for many to have been regarding the different steps involved in processing their application, who is making decisions, how decisions will be made, and how erroneous decisions can be reviewed and reversed. We commend VA for the substantial improvements they have made, but also urge the Department to carefully consider the issues we have raised today as well as the much more detailed comments WWP submitted to the Federal Register. VA must still correct serious flaws in its interim regulation in order to ensure that this program fulfills the intent of the Congress and the promise of the law.

In closing, WWP looks forward to working with VA and with this Committee in bridging these gaps.